

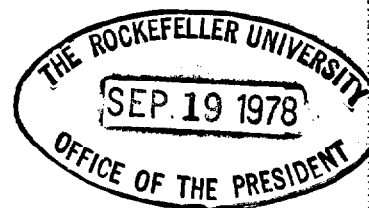
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ASHG Committee to Assess Funding for Human and Medical Genetics

Dear Committee,

I have completed collecting data for our initial report to the Society, and I will summarize the data in this letter. I have in mind making a preliminary report at the Vancouver ASHG meeting of what we have learned so far. For the most part, the report I would like to make will be a description of the data. However, I think the report should end with a brief summary of our collective opinion at this point in time about the status funding for human and medical genetics. For the purposes of developing that collective opinion, I would like to schedule a committee meeting at the Vancouver meeting of the ASHG, early enough in the meeting so that that collective opinion can be organized and expressed at the business meeting. I suggest that we meet on October 4th at 5:00 p.m. in room 201 at the Hotel Vancouver, the site of the annual meeting. Arrangements have been made for a "no host" dinner in that room, which means that you can order your dinner there and charge it to your room if you like. Alternatively, you can wait to have dinner until after the committee meeting. Please let me know as soon as possible whether or not you are coming to the annual meeting, and whether or not there is a conflict with the time I have suggested. Let me turn now to a summary of the data collected so far.

I will deal first with R0-1, or individual grant applications. Two relevant studies have been done. The first is a study by Michael Gough, while he was a grants associate assigned to the genetics program of NIGMS in 1976. The essence is as follows:

- a. In 1976, there were 442 applications to the genetics program of NIGMS, of which 28 were human or clinical (6%). This represents a fall off from 17% in 1974, the last time this was determined.
- b. The median priority score of clinical or human grant applications was 245, versus 215 for non-human grant applications. This 30-point differential is very important in terms of proportion funded, although this wasn't actually determined. In 1974 the medians were 250 human, 190 non-human, even worse.
- c. Looking at grants reviewed by the genetics study section, irrespective of institute assigned, the same trends emerged, i.e., poorer median priorities for human versus non-human applications, and most of the applications (71%) are non-human.

Second, is the study we have done this summer of ASHG members and their RO-1 grant applications to NIH versus all RO-1 applications to NIH. The data from NIH are in and show that ASHG members do as well as the rest of NIH applicants on priority scores and proportion of applications funded. ASHG members have actually done better on dollars awarded, averaging almost \$8,000 more/award over the last 10 years. These figures should be reassuring to any paranoia about the fate of applications from ASHG members, at least in relation to the total universe of applications. These latter figures do not of course deal with specific areas such as human and clinical genetics and genetic counseling, to which I will return in a moment. Also, the figures are not reassuring to any who may have thought of human genetics as a growth field. Applications from ASHG members comprised 2% of all applications in 1968, and only 1.8% so far in 1978. (1978 is not unusual - 1977 is comparable and 1976 is worse.) Since the rate for funding applications of ASHG members is comparable to all of NIH, this also means a slightly smaller share of the total funded applications for ASHG members. Thus, as reflected in these figures, human and medical genetics is not growing quite as fast as the rest of biomedicine in terms of the number of investigators funded.

Putting these two studies together, I would point out first that the human and clinical genetics applications may be a relatively small part of the ASHG applications. For example, in 1976 the genetics program of NIGMS received 442 applications, 28 of them human or clinical. The genetics study section reviewed an additional 44 human or clinical applications which were sent to other institutes, making a total of 72 known human or clinical genetics applications to NIH for 1976. In 1976, ASHG members put in about 200 applications. Thus, even if ASHG members put in all 72 human or clinical genetic applications, this would still only represent about one-third of all ASHG member applications. Thus, the performance of human and clinical genetics grant applications may not be reflected very well in the performance of the Society membership as a whole since non-human applications may dominate the figures.

Summarizing points regarding RO-1 applications:

1. Clinical and human genetics grant applications appear to fare badly. This appears to be true of whether or not the grant application ends up at NIGMS or at a categorical institute. This result could be because the clinical and human genetics grant applications are poorer than other applications, or because they are not evaluated appropriately, i.e., they are compared to non-human applications. Of course, the results could be a combination of both factors.
2. A second major reason for so few funded clinical or human genetic applications, at least as supported by NIGMS, and reviewed by the genetics study section, is the small number of applications.
3. The ASHG membership does average in terms of getting funded at NIH and above average in dollar amount awarded.

4. It appears, however, that the majority of ASHG grant applications may be non-human in subject matter.

The above analysis does not take into account program project and center applications.

For your interest, I include copies of a memorandum from NIH which shows the growth in funding of the genetics program of NIGMS since its inception, related to the growth of NIGMS and to NIH in general. These figures show that genetics support in the genetics program of NIGMS is growing more rapidly than the total budget of NIGMS and keeping pace with that of NIH. However, I hasten to point out that this is not a good measure of the relative growth of funding for human and clinical genetics. With the exception of the genetics centers, it appears that around 90% of the genetics program support is for non-human work. Of course, the genetics centers represent significant funding, somewhat over \$5 million direct costs currently, and to the extent that the centers are carrying out human and medical genetics research, this boosts the total support of NIGMS for human and clinical genetics research to perhaps 20% of the genetics program research budget.

It is difficult to assess funding support in terms of dollars for human and clinical genetics in the categorical institutes of NIH. Genetics is so mixed in with so many diseases that I believe it is virtually impossible to deal with this area. For example, is the recent initiative in diabetes new funding for human and medical genetics? Thus, we must admit of some vagueness in this area. However, if we assume that those applications with a primary thrust in genetics would be reviewed by the genetics study section, we do have the 1976 information that there were 44 such applications. If we assume 33% funding (the overall average for 1976), then perhaps 15 were funded at an average award of \$50,000, adding up to less than one million dollars in 1976.

Finally, I have accumulated a little information from the National Foundation for the years 1975-76 and 1976-77. The national foundation breaks its grants into three categories: clinical, basic, and starter. All grants deal with birth defects, but only a portion deal with what we might call genetic birth defects. That is, their grant applications also deal with acquired diseases such as those caused by viruses. I have reviewed the titles and abstracts from the funded applications for the two years mentioned, and have broken them down into genetic and non-genetic, as indicated in the following table. As can be seen, about 75% of the funded research appears to be genetic in content. Within the 75% genetic funded research, and omitting the starter category, about 20% is clinical. Interestingly, this is fairly close to the proportion of the genetics program of NIGMS which appears to be clinical. As can be seen from the table, the clinical category grew by about 33% between the two years, whereas the basic actually decreased slightly from one year to the next.

Looking at the picture from the total dollars standpoint, the genetics program of NIGMS provides approximately \$5 million direct

costs for genetics centers which have a large component of clinical and medical genetics research. The genetics program of NIGMS also funds some clinical and human genetics research of a non-categorical nature. As of the last measure of this in 1976, it comprised 6% of all funded applications. That being the case, somewhere around an additional two-and-a-half million dollars of the genetics program of NIGMS may go towards human and clinical genetics research. As of 1976-77, the National Foundation provided 1.2 million for clinical and genetics research. An unknown amount of clinical and human genetics research goes on in the categorical institutes of NIH, but in terms of support for grants in which the primary thrust is genetic, the support may be only of the order of \$1 million. The above, then, are the numbers that we have to deal with. Our next problem is to give our assessment of whether the current support for human and clinical genetics is adequate. Obviously, answering this question will have very subjective overtones. One could take the data I have collected on the performance of the ASHG membership and, putting this together with the funding for clinical and human genetics at NIGMS, the National Foundation, and the new initiatives at certain categorical institutes, such as in diabetes, and say that funding for human and clinical genetics is healthy, or at least as healthy as other sectors of biomedicine.

More specifically, the evidence to this point can be enumerated as follows:

1. The median priority scores and the proportion of applications funded for ASHG members is as good as the rest of NIH as a whole.
2. Society members actually attract on an average of \$8,000 more per funded application.
3. Approximately \$5,000,000 direct costs of NIGMS's genetics program budget is assigned to genetics centers.
4. Another two or three million dollars of NIGMS's genetics program budget may go towards funding of clinical and human genetics.
5. As of 1976-77, \$1.2 million of the National Foundation's budget went toward the support of clinical and human genetics.
6. A difficult to define amount of funding in categorical institutes of NIH goes towards human and medical genetics funding.

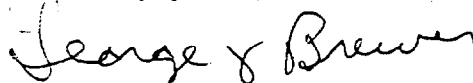
On the other hand, one can make the opposite case:

1. The number of applications for human and clinical genetics, at least as received by NIGMS and reviewed by the Genetics Study Section, is small and appears to be declining.

2. The median priority scores for human and clinical genetics applications are substantially lower than those for non-human applications.
3. The major programs of the categorical institutes which deal with genetic diseases or diseases that have a strong genetic component are not really support of human and clinical genetics for the most part. That is, for example, the initiative in diabetes supports a wide range of studies in this disease, only a small part of which is truly genetic.
4. The identified support for human and clinical genetics is rather modest (perhaps \$10 million).
5. This support is modest particularly in reference to the large number of genetic diseases and other clinical and human genetics problems with which we are faced.
6. There is an alarming fall-off in the amount of research initiated by M.D.'s (see figure in enclosed editorial proof). To the extent that human and clinical genetics is participating in this decline in M.D.-related research, there is cause for alarm that there will be inadequate clinicians to carry out the required clinical genetics research. While inadequacy of funding is surely not the sole reason for this decline in M.D.-related research, we cannot expect a turnaround in any particular field in the absence of adequate funding.

You may all have additional arguments to place on one side of the ledger or the other. In the final analysis, what our committee is asked to do is to give our best judgment of whether or not funding is adequate. Therefore I suggest that we do some thinking about this between now and October 4 and then discuss this area in our committee meeting. Particularly for any one of you who may not be able to make it to the meeting, you may wish to drop me a note concerning your thoughts. In any case, I would like to be made aware of anyone who cannot make it to the meeting or who has a conflict in time.

Sincerely yours,



George J. Brewer, M.D.
Professor, Human Genetics
and Internal Medicine

Chairman, ASHG Committee

GJB:ra1
Enclosures